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Comments of Access Living on Illinois 1115 Waiver Application, January 22, 2014

As an organization led by and for people with disabilities, Access Living emphasizes that waiver services for people with disabilities must reflect consumer control, community choice, and parity for all disability types. Recognition of these concerns can lead to real gains through implementing the 1115 waiver. Ignoring them may produce negative consequences for consumers. Further, the application refers throughout to "patient centered" services. We urge adoption of the distinct, less medicalized, and far more holistic "person centered" approach, which focuses on persons over time and their experiences and preferences.[1]

Available LTSS services (p. 9): The list of services must be expanded to add independent living services, peer support, and peer recovery services as integral services for successful community living.

Social determinants of health (page 1): We commend the State's commitment to tackling the social determinants of poor health throughout all 1115 programs, services, policies, and reforms. In this regard, we urge that the ACE study questionnaire utilized in primary care and shown to be effective in reducing office visits, emergency room visits, and hospitalizations[2] be employed in assessment procedures and provider-patient discussions in waiver-based services.

Improving access to HCBS (pages 5, 31-34): We commend the State's goal of basing services on need rather than on disability diagnosis. This goal also requires that the Universal Assessment Tool (UAT) must be really universal to all disabilities and not limited only to populations currently assessed through the Determination of Need (DON) tool. Real access also involves flexibility, because people with the same functional need may not utilize services in quite the same way or within the same time frame. Some may prefer greater control over their services than others.

Access to services also demands at the procedural level a consumer's right to appeal the determination of needs. In addition, there must be parity for different types of disabilities. Illinois must not promote inequitable service funding for some groups and service cuts for others.

[1] http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3140752/

[2] http://www.cdc.gov/ace/about.htm.

Workforce expansion (pages 10, 24): We commend the State's goal of ensuring that all health professions assume responsibilities to the full extent of their education, training, and ability. Optimal use of ***advanced practice nurses***, for example, has been shown to satisfy the triple aim of good outcomes, high patient satisfaction, and reduced costs.[3] We also strongly recommend optimizing employment of ***people with disabilities*** in the workforce development process, which would satisfy the dual aim of assisting a badly underemployed group and of providing their lived experience and expertise to improve disability competency in health care. Some areas in which the expertise of people with disabilities would greatly contribute to workforce expansion include ***peer support and recovery services and peer navigation*** of the service system and its programs, which are integral to success in community living and the inclusion of which would satisfy one of the four federal requirements that CILs must meet.

The State must specifically optimize use of its already-existing ***certified recovery support specialist*** workforce.[4] These credentialed workers have been shown in other states to be highly effective in assisting people with serious mental illness to self-manage their mental illnesses and other chronic health conditions.[5] In addition to the intensive training required for certification, the cost of attaining certification is high for people rejoining the community after a period of illness, and we urge the State to provide financial assistance to eligible individuals seeking certification.

Nursing facility closure and conversion fund (pp. 19-20): We support the State's incentive program for the closure of nursing facilities but are wary about the effectiveness of conversion. We strongly oppose repurposing SMHRFs. We recommend that procedures for closure be streamlined in order to assure the best community-based outcome and that this fund is ***staffed adequately to speed Illinois towards rebalancing***.

Workforce development and training – Graduate Medical Education (pp. 26-29): We commend the State for its decision to develop a GME program to improve access to health care by underserved populations, but ***we are alarmed that the State's vision of curriculum development does not even mention disability***

[3] http://www.peersnet.org/news/2012-05/john-george-peer-mentor-program-sees-68-percent-decrease-patient-re-hospitalization

[4] http://www.illinoismentalhealthcollaborative.com/consumers/consumer_crss.htm

[5] http://www.peersnet.org/news/2012-05/john-george-peer-mentor-program-sees-68-percent-decrease-patient-re-hospitalization

competency (p. 28). The absence of professional training on disability competency for health care practitioners is a highly significant barrier to appropriate and effective health care.[6,7]

While we support ***voluntary*** training of personal attendants or home care workers, we stress that ***mandatory training of personal attendants or home care workers can be a deterrent to development of this work force and an impediment to consumer control and self-direction.*** When a person with a disability must hire a worker quickly or prefers to train the worker him/herself, flexibility should be allowed.

Reducing the PUNS waitlist (p. 35): We are pleased to see that the State understands the need to reduce the PUNS waiting list for services by analyzing and correcting overestimates of the number of individuals who are actually waiting for DD services currently. PUNS is often cited as a reason why Illinois should be chary of opting into the ***Community First Choice Option (CFCO)***, which would produce an additional ***6% federal match*** for HCBS services that Illinois has hitherto lost due to its failure to adopt this program. The CFCO also would provide the framework to expand existing services to all, facilitate provision of HCBS in a genuine community setting, be consistent with the State's goals of eliminating institutional bias and basing eligibility on assessed needs rather than on diagnosis or age, and mandate consumer feedback that is essential to assure that the program is operating effectively.

We are alarmed, however, that the application requests in a different section permission to "operate a waitlist for HCBS" (p. 48), implying that the PUNS waitlist for DD service recipients will be eliminated at the expense of other service recipients who will be placed on newly-created waitlists. The State itself acknowledges in its Disability Waiver that *McMillon v. McCrimon*, 807 F.Supp. 475 (1992), held that the Home Services Program is an entitlement that forecloses the possibility of a waiting list.

Quality incentives and outcomes (p. 36): We recommend a measure of the quality of care transitions as people move from institutional care to waiver services and community to waiver services. ***The Care Transition Measure (CTM)*** developed by the University of Colorado has been endorsed by CMS and scholars, and we encourage that it be utilized to maximize success in the transition phase.

[6] http://www.ncd.gov/publications/2009/Sept302009#Professional

[7] http://minorityhealth.hhs.gov/Assets/pdf/Checked/1/ACMHHealthDisparitiesReport.pdf

Inclusion of SMHRFs as funded entities (pp. 39-40): ***We strongly oppose the State's proposed waiver of the IMD exclusion for Specialized Mental Health Rehabilitation Facilities (SMHRFs).*** First, it is not even clear that Title XIX allows waiver of the IMD exclusion under an 1115 waiver. The provisions of 42 U.S.C. 1396d, including the IMD exclusion, are not among those permitted to be waived under the 42 U.S.C. 1315(a) waiver authority concerning 1115 waivers. The waiver of the IMD exclusion is also unacceptable as a matter of policy. ***Even rebranded as SMHRFs, these facilities are still IMD nursing homes in which thousands of people with mental illness have languished for decades.*** They routinely restrict resident rights and liberties and do little to promote recovery. Despite their limitations, recent legislation, opposed by Access Living, expands their reach and authority to include additional services[8] that they are, in our view, ill-equipped to provide. Rather than fostering community integration, creating multiple levels of institutional care will likely instead result in individuals going nowhere. The draft SMHRF regulations do not adequately address how individuals will be assured services in appropriate community settings once they land in a SMHRF. If the State wants to reduce its reliance on institutional settings, as it asserts throughout its draft waiver application, it must develop and enhance integrated community services, not simply dress up its failed institutions. Instead of using 1115 waiver funds to support SMHRFs, those resources should be invested in incentivizing HCBS.

Supportive housing (pp. 40-41): We support incentivizing permanent supportive housing, an evidence-based intervention that works well for people with serious behavioral issues or very complex health needs. However, many people with disabilities who have Medicaid and who do not need much, if any, case management do have a dire need for rental subsidies, one of the major barriers for people who want and are otherwise eligible to leave nursing facilities. The barrier is also not temporary; simply receiving SSI does not guarantee any type of ongoing rental subsidy. We urge Illinois to consider the use of "flexible services" funds for non-supportive housing rental subsidies.

Approach to evaluation (pp. 46-47): The application refers in passing to "recipient satisfaction surveys" in the context of *design* of evaluation elements but *not performance* evaluation. Consumer satisfaction as to performance is absolutely essential to a proper assessment of the success of the waiver services.

[8] While the application refers to acute stabilization, intermittent stays and long term services and supports, the legislation provides for triage, crisis stabilization, transitional living units, and long term supports. In no instance is a person to be admitted to any of the SMHRF LOCs who meets the criteria of involuntary admission pursuant to Section 5/1-119 of the MHDD Code (405 ILCS 5/1-100 *et. seq*.)

Reasonable promptness (p. 48): We reiterate that there should be ***no waitlists*** at all for HCBS. See, e.g., *McMillon v. McCrimon*, 807 F.Supp. 475 (1992) [Home Services Program is entitlement foreclosing use of waiting list]. To ensure promptness, the State should take advantage of the CFCO.

Amount, duration, scope of services and comparability (p. 48): Service cost maximums are not indicative of a system focused on individual need. They are instead an institutional practice forced on HCBS and should have no place in HCBS service provision. The application's language regarding Medicaid-ineligible seniors who will nevertheless receive services is unclear, and we are concerned that this allows seniors a higher asset level than younger people with disabilities, an inequitable result.

Expenditure Authority Waiver Requests (pp. 49-51): We oppose funding for SMHRFs and SODCs under the 1115 waiver. These settings are institutional, not community-based.

Appendix X – Listed services (pp. 52 *et seq.*): ***There are three services currently provided under the 1915 waivers that are not included in the list of services in Appendix X.*** Those are placement maintenance counseling, nurse training, and assisted living. In no event should a new 1115 waiver *omit* services already in existence. ***We are also concerned with the definition of Personal Assistant as one of the most dangerous parts of this proposal.*** The definition notes that services should be at home and at work, but does not state "community." Many consumers need help with shopping and errands, for example. We are concerned that this weak definition encourages use of Home Health Aides rather than Personal Assistants, because the tasks ascribed to Home Health Aides are in fact ones that Personal Assistants can and should have the flexibility to perform. It is unclear whether the draft proposal includes CILs in its vision, and ***Centers for Independent Living need to be in the forefront and clearly defined in the HCBS service definitions*** as providers of services that range across a number of the definitions in the draft, such as independent living skills training, support, activities, transition services, home modifications, and so on. Finally, ***we oppose the use of 1115 funds to pay subminimum wages, which are contrary to the goals of independence and self-sufficiency.***

Please contact Tom Wilson at 312-640-2125 with any questions about the above comments.

Submitted by Amber Smock, Director of Advocacy.